

National Cancer Advisory Board (NCAB)
ad hoc Subcommittee on Population Science, Epidemiology, and Disparities

Gaithersburg Marriott Washingtonian Center
Gaithersburg, MD
December 2, 2019
5:30 – 7:00 p.m. EDT

SUMMARY

Subcommittee Members:

Dr. Electra Paskett, Chair
Dr. Francis Ali-Osman (absent)
Dr. Deborah Bruner
Dr. David Christiani (absent)
Dr. Judy Garber (absent)
Mr. Lawrence Gostin (absent)
Dr. Elizabeth Jaffee (absent)
Dr. Beth Karlan (absent)
Dr. Mack Roach (absent)
Dr. Margaret Spitz (absent)
Dr. Deborah Winn, Executive Secretary

Other Participants:

Dr. Nelson Aguila, NCI
Dr. Michelle Bennet, NCI
Dr. Melissa Bondy, Stanford University, Board
of Scientific Advisors (BSA)
Dr. Otis Brawley, BSA
Dr. Jessica Calzola, NCI
Dr. David Chambers, NCI
Dr. Robert Croyle, NCI
Dr. Carol Ferrans, BSA
Dr. Howard Finegert, BSA
Dr. John Greene, Booz Allen Hamilton

Dr. Andrea Hayes-Jordan, The University of
North Carolina, NCAB
Dr. Karen Knudsen, BSA
Dr. James Lacey, BSA
Dr. Douglas Lowy, NCI
Dr. Peter Ogunbiyi, NCI
Dr. John Ojeifo, NCI
Dr. Diane Palmieri, NCI
Dr. Kimrya Rathmell, BSA
Dr. Les Robison, St. Jude, BSA
Dr. Norman E. Sharpless, NCI
Dr. Sudha Sivaram, NCI
Dr. Sanya Springfield, NCI
Dr. Shobha Srinivasan, NCI
Dr. Emmanuel Taylor, NCI
Dr. Muluaem Tilahun, NCI
Dr. Susan Vadaparampil, Moffitt Cancer
Center
Dr. Mary Ann Van Duyn, NCI
Dr. Stacey Vandor, NCI
Dr. Anil Wali, NCI
Dr. Tiffany Wallace, NCI
Dr. Cheryl Willman, BSA

Ms. Alicia Rosov, The Scientific Consulting
Group, Inc., Rapporteur

Welcome and Opening Remarks

Dr. Electra Paskett, Director, Division of Cancer Prevention and Control, College of Medicine, The Ohio State University

Dr. Electra Paskett welcomed the participants, including Dr. Norman E. Sharpless, Director, National Cancer Institute (NCI), and Dr. Douglas Lowy, Deputy Director, NCI. Dr. Sharpless expressed his appreciation for the work of this subcommittee, which has a tremendously important mission. He welcomed both new and returning members of the subcommittee, thanking them for their service. Participants introduced themselves, and Dr. Paskett reviewed the meeting's agenda.

NCI Update on Implementation of Recommendations from the Working Group Report on Cohorts
Dr. Deborah Winn, Acting Director, Division of Cancer Prevention, NCI

Dr. Deborah Winn explained that the *ad hoc* Subcommittee consists of members of the NCAB, but the work is done through working groups. The Working Group on Cohorts submitted its report to the Board in June, and the NCI has been digesting that information regarding what the research community needs in terms of cohorts. Dr. Joanne Elena, Division of Cancer Control and Population Sciences (DCCPS), NCI, will deliver to the NCAB a presentation about survivor cohorts that factors in some of the Working Group's recommendations. The Division of Cancer Control and Population Sciences is considering how it will go forward with new cohorts and may issue a Request for Information to solicit information regarding research needs in cohorts. The Division of Cancer Prevention is thinking about how to implement the Working Group's recommendation that prevention trials include more content earlier on, because the data from prevention trials are an enduring research resource.

Dr. Paskett thanked Dr. Winn for this summary and acknowledged the work that had been undertaken in response to the report of the Working Group on Cohorts. The subcommittee has been discussing what topic it should address next and, in consultation with NCI leadership, decided to closely examine disparities in the NCI. The two presentations at this meeting will outline the current state of diversity training and research on cancer health disparities at NCI.

Update on Diversity Cancer Training

Dr. Peter Ogunbiyi, NCI Center to Reduce Cancer Health Disparities (CRCHD)

Dr. Peter Ogunbiyi thanked the Subcommittee for the opportunity to present information about the Diversity Training Branch. He describe the Continuing Umbrella of Research Experiences (CURE) program, an NCI diversity training program for students and investigators. Its objectives have not changed in 20 years: (1) Increase the size of the talent pool, (2) emphasize the scientific areas of greatest need, and (3) expand and extend the period of training. The strategies to achieve those objectives have, however, changed. For example, the program now begins trying to attract participants in middle school, not high school. Most of the participants are undergraduate or graduate students, but 17 percent are high school students, and the bulk of undergraduate student participants entered CURE in high school. The majority of CURE participants are Hispanic or African American; efforts are ongoing to attract participation from other minority groups. Dr. Ogunbiyi stressed that CURE is more than a pipeline: Its success can be attributed to the ecosystem of support that trainees receive. A key element is the peer network, helping trainees navigate through the NIH system. The mentorship, professional development, and passionate involvement of the peer program members are foundational to the program's success.

Dr. Ogunbiyi explained that the CURE program offers diversity supplements attached to NCI grants. The distribution of diversity supplements and trainees across divisions indicates that trainees are most interested in basic science—the Division of Cancer Biology supports more awards than other divisions. Other funding mechanisms include National Research Service Awards (F31) and K awards. The demographics are consistent across funding mechanisms, with Hispanics and African Americans comprising most of the trainees and women outnumbering men. CURE trainees have similar success rates for obtaining R01 awards as other National Institutes of Health (NIH) K awardees. However, African American CURE trainees were more successful in competing for small grants than African American researchers at NIH who were not part of CURE. Dr. Ogunbiyi mentioned that iCURE—the Intramural CURE program for postbaccalaureate and graduate students—is now accepting applications.

The Youth Enjoy Science (YES) R25 was initiated in November 2016 to fill a gap. The goals of the program are to engage students from diverse backgrounds—and their teachers—in cancer research; to inspire interest in biomedical sciences and cancer research; to help students envision cancer research as a

career path; and to strengthen practical research and career skills. A pilot program in Baltimore was successful, and YES now funds 11 grants in 10 states. Most of the programs are on the two coasts, indicating that reaching the center of the country is a challenge. The demographics of the YES program are different from the other programs in that 28 percent of the participants are American Indian/Alaska native, a very exciting success. The challenge currently facing the YES program is lack of funding; in the current cycle, they expect to be able to fund only two out of 40 applications.

Dr. Ogunbiyi concluded by sharing the immediate goals of the CRCHD: to increase funding for the YES program; to build a pipeline of diversity-focused training; to promote training in quantitative sciences, such as data sciences; to continue enhancing cancer health disparity research; to improve the competitiveness of postdoctoral fellows; and to improve the tracking of trainees to better evaluate the impact of the CRCHD's programs.

Update on NCI Minority Health and Health Disparities

Dr. Emmanuel Taylor, NCI CRCHD

Dr. Emmanuel Taylor explained that part of the mission of the CRCHD is to advise the NCI leadership on strategic priorities, program directions, and scientific policy to strengthen cancer disparities research and diversity training. The annual Minority Health and Health Disparities (MHHD) Report is congressionally mandated and is an invaluable tool for documenting the activities and progress being made. Dr. Taylor noted that health disparity populations include not only racial and ethnic minority populations, but also rural residents, people of less privileged socioeconomic status, and sexual and gender minorities.

Dr. Taylor described the process for MHHD report, the data for which are drawn from the portfolio of all funded grants. The Program Directors from all the NCI Divisions, Offices, and Centers (DOCs) assign codes to every grant in the portfolio they manage; the codes pertain to representation of different groups in the study population. Coding has been largely a manual process, but parts of it were automated 2 years ago. NCI's total funding for health disparities research has increased dramatically in the last 2 years, from \$289 million in fiscal year (FY) 2016 to \$471 million in FY 2018. Most of the funding comes from DCCPS; all of its money is coded as "clinical." The CRCHD is the only DOC that has coded funding in all areas of research—basic, clinical, outreach, and training. minority health and health disparities funding has tended to be 5–6 percent of the total NCI budget; in FY 2018, it was 7.9 percent.

Dr. Taylor reviewed the NCI's efforts to address cancer health disparities, noting that the NCI is addressing many areas, including basic research, clinical and community-based trials, surveillance, and portfolio analysis. The NCI Community Oncology Research Program (NCORP) is critical for increasing participation of rural populations and other underserved groups in clinical trials. DCCPS has made a tremendous effort in increasing attention to rural health disparities research. Surveillance has been key to understanding the geographic distribution of cancers, and the combined efforts of Surveillance, Epidemiology, and End Results (SEER) and the Centers for Disease Control provide that understanding on different levels. Genomics is becoming more important because of the biological aspects of disparities. The Partnerships to Advance Cancer Health Equity (PACHE) is now the flagship program of the CRCHD and has within it the full spectrum of research.

The Trans-NCI Cancer Disparities Activities Committee (CDAC) was initiated in March 2019 and is co-chaired by the CRCHD and the Center for Research Strategy. It serves as a central hub of cancer disparities activities across the NCI and supports research and initiatives that mitigate both the biological and nonbiological factors that contribute to cancer disparities. The Trans-NIH MHHD Reporting Working Group is charged with examining the purpose of and current procedures used for MHHD reporting at NIH and determining whether improvements can be made. Its efforts are directed toward shaping the NIH 5-year strategic plan.

A significant challenge that the CRCHD faces is the large number of grants that must be coded each year—approximately 2,000 NCI grants meet the reportable threshold. Intramural projects and sub-projects must also be coded, and it is difficult to tease out the amount of money associated with each protocol that applies to a minority population. The reportable threshold changed from 25 percent to 30 percent in FY 2017 to reflect the increase of minorities in the U.S. population.

Opportunities for improvement include —

- Automating MHHD data collection and retrieval; even so, verification and validation by the Program Directors still would be required.
- Automating data retrieval and interface with relevant data sources; for example, linking with the Human Subjects System.
- Enabling batch submission of data.
- Retaining NCI's ability to collect data internally.
- Supporting in-depth analysis for NCI—for example, analyzing cancer continuum research in specific disparities populations using Common Scientific Outline (CSO) codes.

Discussion

Dr. Paskett thanked Drs. Ogunbiyi and Taylor for their presentations and opened the floor for discussion.

Dr. Sharon Willman noted that the CRCHD has good ways to code the participants in the training programs and asked if it was possible to track the populations included in the study populations of funded programs. Dr. Taylor confirmed that the Program Directors code the study population, and the data can be extracted to identify who is looking at a particular cancer in a specific population. That information could measure whether the NCI portfolios are reaching certain populations and could identify needs that are being missed. More recent requests for applications have been asking those questions, and it is encouraging to see the increase in minority health and health disparities funding.

Dr. Lowy commented that Dr. Eliseo Pérez-Stable, Director of the National Institute on Minority Health and Health Disparities, has wanted to establish a health disparities registry. The concept is straightforward to NCI and cancer researches, but it is controversial in other NIH Institutes. Disparity research is not controversial in cancer, but it is in other disease areas.

Dr. Willman observed that tissues that can be pulled from SEER are gold mines for future research.

NIH and NCI Definitions of Cancer-Related Disparities

Dr. Deborah Winn

Dr. Winn referred participants to the definition provided in their materials and explained that the NCI is required to report data in a specific way for the MMHD report. Dr. Paskett suggested that age also is a group relevant to cancer research that should be called out.

Brainstorming: Scope of the Working Group Report on Disparities, Portfolio Analysis Specifications, and Additional Expertise Needed for the Working Group

To open the brainstorming session, Dr. Paskett referred to Dr. Taylor's statement that "analyzing cancer continuum research in specific disparities populations" presented an opportunity for improvement. She

suggested that concept as a foundation for a matrix that could identify gaps in the NCI portfolio, with the cancer continuum across the top and the populations on the vertical axis.

The CSO research codes outline the cancer continuum as follows: biology; etiology; prevention; early detection, diagnosis, and prognosis; treatment; cancer control, survivorship, and outcome; and scientific model systems. A participant asked where access to care and health delivery research fit in the categories; Dr. Paskett thought they could fit broadly under cancer control and survivorship.

Dr. Les Robison asked whether the charge is exclusively to evaluate the existing portfolio, or whether it includes examining gaps in knowledge. SEER has given good information about incidence and mortality, but researchers do not know about access to care or where the disparities exist. Dr. Otis Brawley stated that the population science group has done a good job of studying that and has published information. Dr. Robison suggested that the group should identify where the data are missing as a step in evaluating whether NCI's portfolio is addressing those gaps. Dr. Sharpless commented that it would be difficult to develop that type of data because the codes do not exist. A more useful question for the Work Group to address would be, "Are there topics NCI should fund that it is not funding? Or areas of past focus that should no longer be funded?"

A participant commented that this charge will likely require expertise in data science and metadata. Dr. Sharpless mentioned a tool that Dr. James Anderson, Office of the Director, NIH, used for grant analysis to identify the funding success rates by research cluster. That tool may or may not be useful for this Work Group.

Summary and next steps

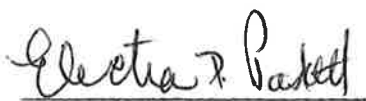
The charge for the Cancer Disparities Working Group is to examine and identify gaps in the NCI portfolio by populations across the cancer continuum and provide suggestions for NCI to address those gaps.

Dr. Paskett stated that she and Dr. Winn will contact current Subcommittee members to confirm their willingness to serve in the new Working Group. She asked participants to email recommendations for the expertise required for the Cancer Disparities Working Group, specifically requesting a range of experts across disciplines. Dr. Winn reiterated that Working Group members do not need to be members of the Subcommittee and should include outside experts.

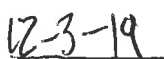
Most of the Working Groups have been conducted by teleconference, with a single 1-day face-to-face meeting to identify all the issues and perspectives. The time frame for a deliverable report is indeterminate: It will take however long it takes; the final report will be delivered to an NCAB meeting, and interim reports can be submitted as needed.

Adjournment

Dr. Paskett adjourned the Subcommittee meeting at 7:01 p.m. EDT.



Dr. Electra Paskett
Chair



Date



Dr. Deborah Winn
Executive Secretary



Date

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